



Evans, J. (2017) Life After Encephalitis: A Narrative Approach. *Brain Injury*, 31(4), p. 567. (doi:10.1080/02699052.2016.1274782) [Book Review].

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.gla.ac.uk/140429/>

Deposited on: 9 May 2017

Enlighten – Research publications by members of the University of Glasgow
<http://eprints.gla.ac.uk>

Book Review

Life After Encephalitis: A Narrative Approach

Ava Easton (Psychology Press, 2016). [200 pp.] £14.99 (softcover). ISBN: 1138847216

Jonathan Evans (jonathan.evans@glasgow.ac.uk)

Mental Health & Wellbeing, Gartnavel Royal Hospital, University of Glasgow, Glasgow, UK

This is a wonderful book, one of the 'After Brain Injury; Survivor Stories' series. Ava Easton says in the preface to *Life After Encephalitis* that she hopes that it gives a voice to survivors of encephalitis. It does. It is a book of stories from which we learn what encephalitis is and how it affects the brain, but more importantly how it changes the lives of those who survive it.

The book introduces the reader to encephalitis, its various forms, and the basics of the approaches to diagnosis, treatment and prevention, focusing on the consequences of encephalitis and highlighting the hidden disability associated with acquired brain injury, and the impact on identity. This is useful, but it is the survivors' stories that are so captivating.

Easton makes a compelling case for the use of narratives in helping survivors, their families and health care practitioners to understand what it means to cope with the consequences of encephalitis. Narratives are the stories that reflect the lived experience of a condition, the way that people make sense of their experience and situation. The history of use of narratives in medicine is discussed. Easton notes that early medical practitioners had to listen to their patients because they did not have sophisticated technologies to help in diagnosis or treatment. The advent of such technologies perhaps led some doctors to listen less to their patients' stories. But of course, despite the sophisticated technologies, we cannot take away all of the negative consequences of conditions and so we have started to listen again to people with chronic conditions in order to better understand their experiences and to be in a better position to offer support. The case for narratives, however, is really made for Easton by the survivors of encephalitis and the families who tell their stories in this book with such clarity, insight and dignity.

The unique accounts of survivors Roy, Sophie and Ross are annotated by the expertise of Prof Solomon and Dr Irani, which is a wonderful way to understand and learn about the consequences of encephalitic illnesses. That encephalitis changes the lives of those who suffer it, is clear, but it also changes the lives of family members, friends and colleagues. Jean Evans provides a deeply moving account of how the lives of her husband, Phillip, and herself changed when Phillip developed encephalitis. Then, Janet Hodgson gives us a very helpful neuropsychological account of Phillip's experiences that illustrates how encephalitis leads to a complex interplay of cognitive, emotional

and behavioural changes that has a profound effect on a person's sense of identity. This style of combining a survivor's story with a health care professional's perspective is engaging and effective.

Losing a child is perhaps the worst thing that can happen to a parent. In Chapter 7, Tiggy Sutton describes the trauma of losing her son, Johnny, who died after just a four-day encephalitic illness. When Johnny did not make it, Tiggy Sutton's family had to find a way to cope. They coped 'minute by minute, hour by hour, day by day'. For those who suffer from the same experience, this chapter will, I hope, give comfort—Tiggy Sutton articulates the terrible experience that she, her husband and their other children had to endure, but she also explains how they managed to find a way to cope. I was reminded of the book written by Professor Barbara Wilson, the President of the Encephalitis Society and her husband Mick—*First Year, Worst Year*—which describes how she and her husband Mick coped with the loss of their grown-up daughter Sarah who died in a white water rafting accident in Peru. Tiggy Sutton and also Barbara and Mick Wilson take the reader through the experience of loss, never avoiding describing the emotional pain they experienced, but they also explain how they were able, in time, to cope with a loss, which at times felt intolerable. As Tiggy Sutton says, 'Our grief has eased, but it has never disappeared'.

Resilience is a theme that characterizes the survivors and their family members in this book. Roy puts it well when he says, 'Do I wish I had never had the illness—of course. But I am a better person for having it'. Jean Evans comments, 'Encephalitis has changed both of our lives, but it hasn't stopped them. We have lived through the tough times and changed for the better'. These and the other stories in this book not only help us understand how encephalitis robs people of many things, but also show that many people grow stronger as a result of their experience with encephalitis.

If you work with people who have experienced encephalitis (or indeed any form of brain injury), or are ever likely to, I would recommend reading this book.